Data Resources

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THE UNMET NEED

Our community is currently facing an information problem. There exist disparate discordant datasets for our community that impede our ability to improve outcomes for those living with epilepsy.

OUR GUIDING PRINCIPLE

The more that data is accessible and available, the quicker data can be converted into value and action.

OUR SOLUTION

To build an informatics infrastructure needed to be able to facilitate data aggregation, data insights and recommendations derived from those insights. Our ultimate purpose is to improve the outcomes of those living with epilepsy.

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Epilepsy
Data Platform
on Physiological
Measurements

EPILEPSY ECOSYSTEM PLATFORM

Current Data

1. Kaggle contest data (preictal/interictal)
2. Seizure only data
3. Full Neurovista dataset (by invitation for independent evaluation)

Future Data (via My Seizure Gauge)

1. Wearables: EEG, ECG, EMG, accelerometry, electrodermal, blood oxygen

2. Implantables: intracranial EEG/DBS, sub-scalp EEG

EPILEPSY ECOSYSTEM

EPILEPSY ECOSYSTEM PLATFORM

Not just a data sharing platform but:

Promoting crowdsourcing and independently evaluate solutions to deep problems in epilepsy (e.g. seizure forecasting)

EPILEPSY ECOSYSTEM PLATFORM

powered by **seer**

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Data can be viewed on the web and downloaded from the SeerCloud using APIs

Activity (as of 4/2019)

- Registered with the ecosystem: 176

- Participating in the Github organization: 100

- Working with data: 63

Register at www.epilepsyecosystem.org

For more details see Kuhlmann et al., 2018, *Brain*

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Epilepsy Educational Resource Wiki
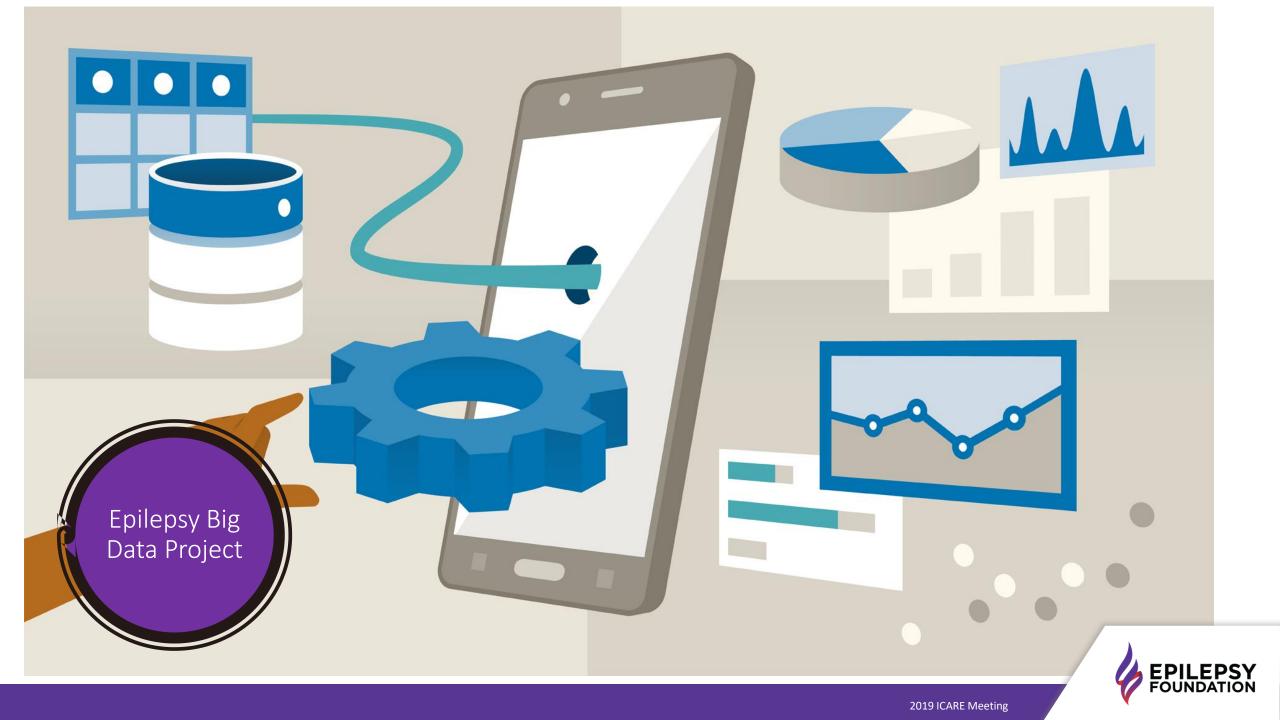
PIPELINE TRACKER

Epilepsy.com/pipeline
Site to go live on May 23, 2019

Epilepsy.com/deviceapedia
Site to go live on May 23, 2019

- **Provide visibility** to therapies and devices in the epilepsy pipeline

- **Create a rich educational resource** through the search and filter feature that would allow for quick comprehensive landscape assessments on the epilepsy pipeline

- **Promote partnerships and innovation** among industry, academia, investors, and physicians by de-siloing the community and highlighting unmet needs of our community

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Epilepsy Insights
Data Resource
"Epilepsy Life Coach"

Epilepsy Big Data Project

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Rare Epilepsy Network >1450

I&R Helpline >60,000 calls logged

Claims Data

Epilepsy Learning Health System

Human Epilepsy Project 700

We have the ecosystem components, but no way to bring the data together to provide a return of results to our users

Diary
stered

Grass
>100,000

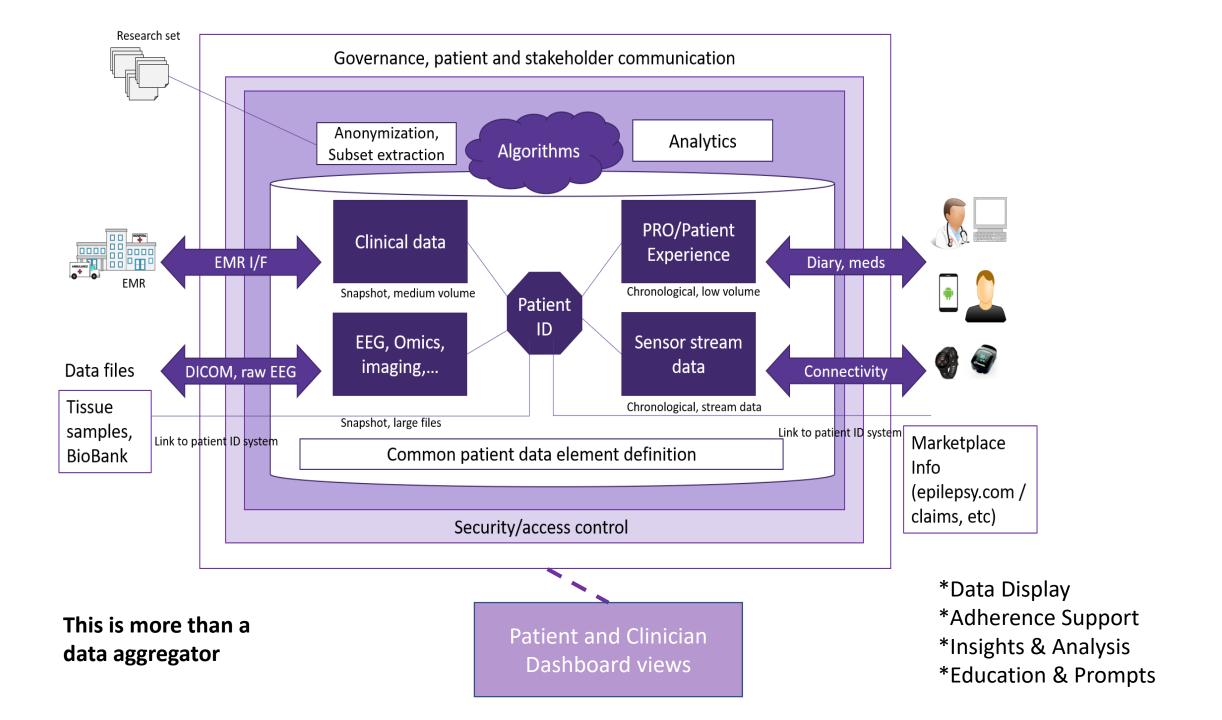Epilepsy.com
1 Million users per month

Professional Education Training >50,000

Social Media >150,000

MSG: Wearables / other mobile diaries

Example Data Stream Assets

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Research set

Governance, patient and stakeholder communication

Anonymization, Subset extraction

Algorithms

Analytics

Clinical data

Snapshot, medium volume

EMR I/F

EMR

PRO/Patient Experience

Chronological, low volume

Diary, meds

Patient ID

EEG, Omics, imaging,...

DICOM, raw EEG

Data files

Tissue samples, BioBank

Link to patient ID system

Snapshot, large files

Sensor stream data

Chronological, stream data

Connectivity

Link to patient ID system

Marketplace Info (epilepsy.com / claims, etc)

Common patient data element definition

Security/access control

This is more than a data aggregator

Patient and Clinician Dashboard views

*Data Display
*Adherence Support
*Insights & Analysis
*Education & Prompts

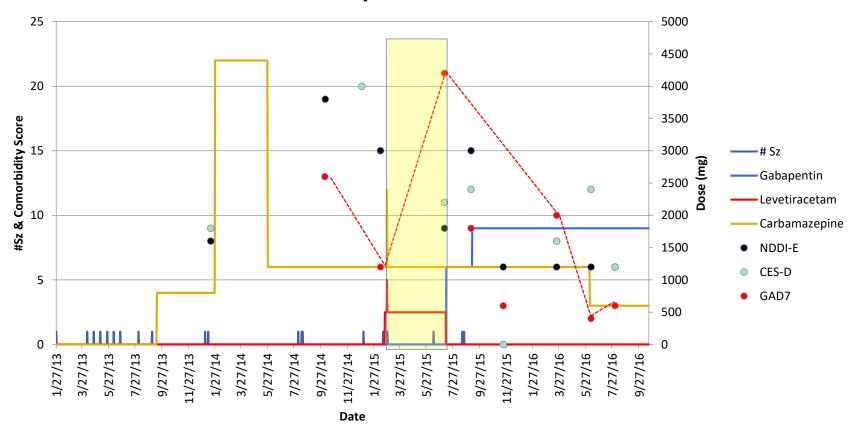# WHAT SETS US APART FROM OTHER DATA COMMONS PLATFORM

As a patient advocacy organization – people living with epilepsy are our primary focus

We want to empower them with the tools they need to succeed and ensure that they are partners in the process. Therefore the patient dashboard and user-feedback are critical components to the platform

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EXAMPLE OF DATA WE COLLECT THAT COULD BE VISUALIZED

AED & Comorbidity Scores over Time

Data from HEP project - visualize insights for action (GAD7 – Levetiracetam)

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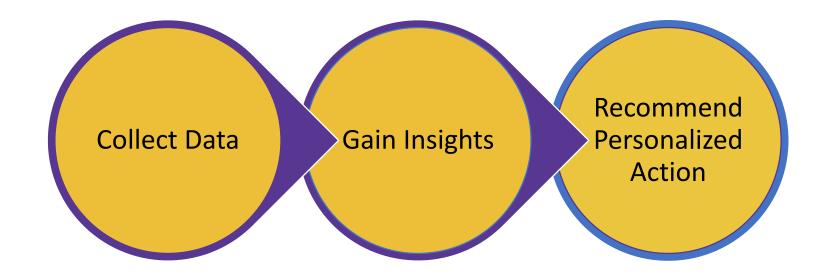# EXAMPLE OF DATA WE COLLECT THAT COULD BE VISUALIZED

- Data in the last slide was messy and not user-friendly

- Data suggested that Levetiracetam influenced GAD7 levels (anxiety)
  - There was no return of results to the participant.

- As a Foundation – those impacted by epilepsy are our primary focus – our goal is to provide personalized actionable insights
  - For us to do this all stakeholders should be involved to maximize impact and meaningfulness.

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THE GOAL

Improve outcomes for those living with epilepsy

THE PROCESS

Collect Data → Gain Insights → Recommend Personalized Action

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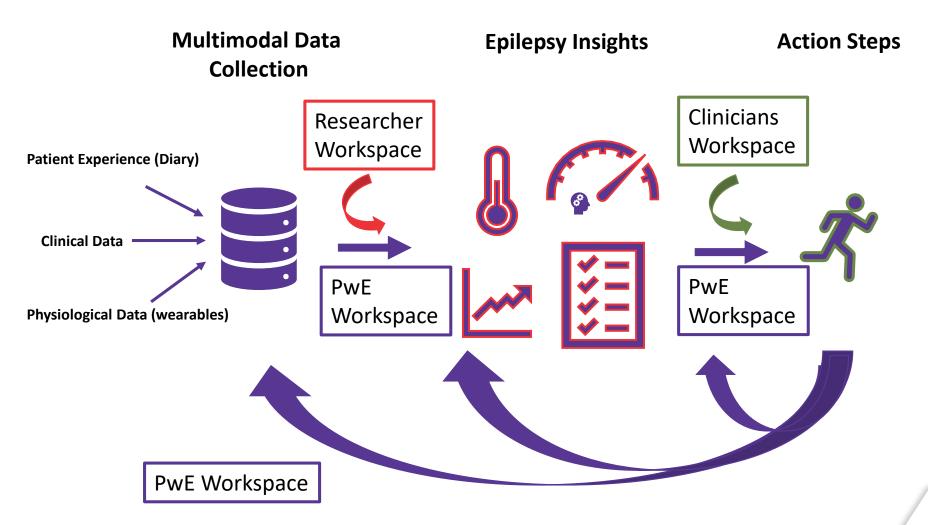# WHAT INSIGHTS MATTER? WHAT INSIGHTS LEAD TO ACTIONS THAT IMPROVE OUTCOME?

- Studies suggest that some individuals might have triggers for their seizures – but what are those triggers?
- Studies suggest that most individuals have patterns to their seizures – what are those patterns?
- What therapies work best for the individual?
- Are there behavioral changes that could help improve health outcomes?

We want to help individuals take back some control:

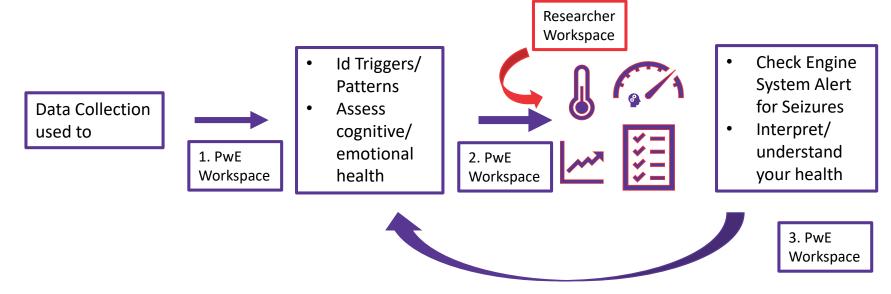Collect Data -> Gain Insights -> Recommend Personalized Action

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The Foundation Life Coach Tool:
Empowering the epilepsy community to take action

Multimodal Data Collection

Epilepsy Insights

Action Steps

Patient Experience (Diary)

Clinical Data

Physiological Data (wearables)

Researcher Workspace

PwE Workspace

Clinicians Workspace

PwE Workspace
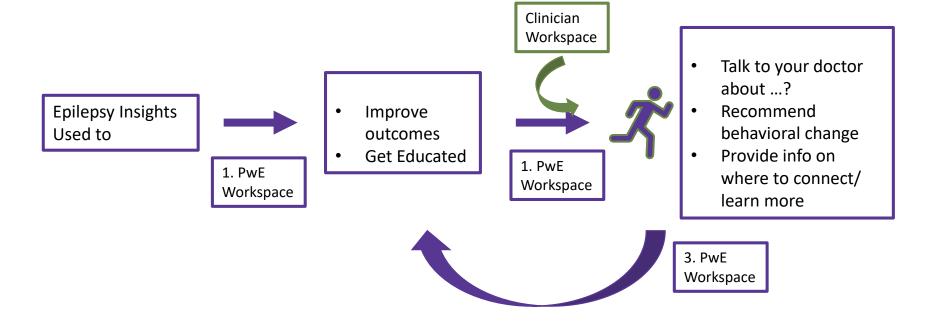
PwE Workspace

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EXAMPLES OF THE TOOL

1. PwE can aggregate their health data as they choose
2. PwE can decide which insights they are interested in tracking. They can also opt in to research workspace for development of new algorithms
3. PwE provides feedback on user design and usefulness of reports for their own day to day life experience

*For those that opt-in, researchers can build upon their data to optimize future insights
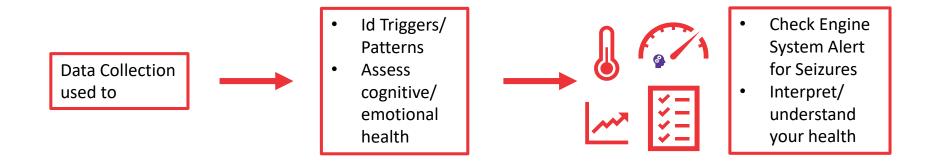
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EXAMPLES OF THE TOOL

1. PwE can set reminders based on insights for themselves
2. PwE can decide to work with clinicians to get additional recommendation – also could feed into the LHS ecosystem
3. PwE provides feedback on user design and usefulness of recommendations.

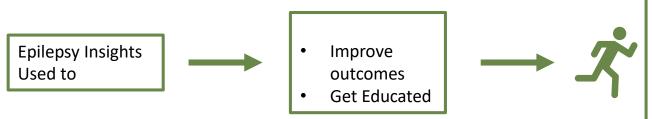*For those that opt-in, clinicians can build upon their data to optimize personalized recommendations

LEVERAGING ONGOING INITIATIVES WITH RESEARCHERS

| Data Collection used to | → | • Id Triggers/ Patterns
• Assess cognitive/ emotional health | → | (icons) | • Check Engine System Alert for Seizures
• Interpret/ understand your health |

- My Seizure Gauge (assessing physiological changes and diary report for seizure forecasting)
- Rare Epilepsy Network (natural history study through caregiver report)
- Understanding individual drug response, and linking outcomes to omics, genomics, phenotype.
- Assessing efficacy of various seizure counting devices

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LEVERAGING ONGOING INITIATIVES WITH CLINICIANS

Epilepsy Insights Used to →
- Improve outcomes
- Get Educated

→

- Here is a discussion guide on what to talk to your doctor about on your next visit …?
- Recommend behavioral change
- Provide info on where to connect/ learn more

- Managing Epilepsy Well Network

- Epilepsy.com

- Epilepsy Learning Healthcare System

- Human Epilepsy Project

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ROLE OF THE FOUNDATION

This is an aggregator/visualizer tool. With Foundation's role being the interface for the communication
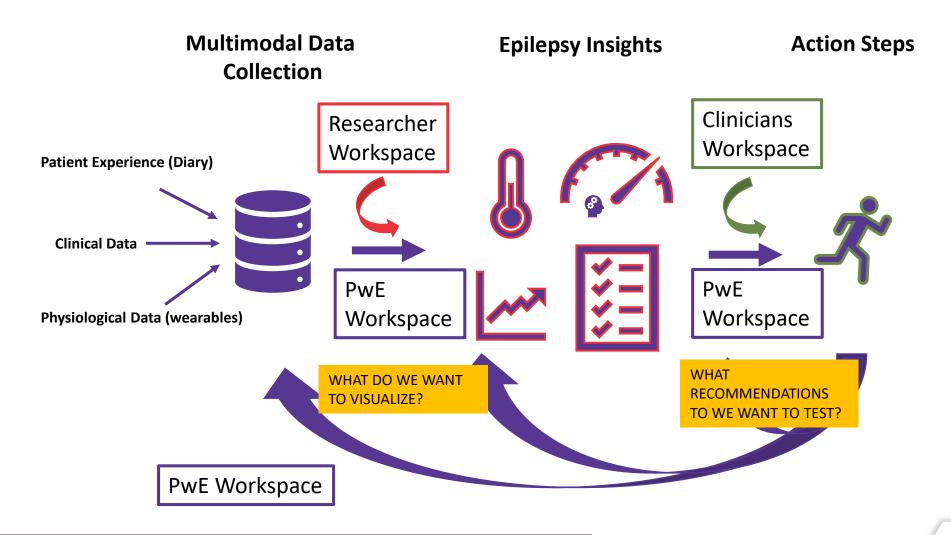
System can be agnostic to the data streams coming in (including other diaries).

This is an open-sourced initiative – Foundation develops the aggregator platform on code that other developers can build upon. Our vision is that any development tool built off of this platform is shared with the community

The value of this tool is in the epilepsy life coach: Providing recommended action steps based on data collected

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FOUNDATION LIFE COACH: EMPOWERING THE EPILEPSY COMMUNITY TO TAKE ACTION

OVERVIEW OF OUR PROCESS

- STEP 1: Bring existing data sets (i.e. HEP or open-label studies) into the system to develop insights
  - These insights will form the basis of our pilot visualizer
    - Example: Compare diary data as a drug ramps up in a trial

- STEP 2: Follow a curated set to pilot prospective personalization (from insights gleaned above)
  - Would need discovery forms to vet seizures
  - Test insights and recommendations

- STEP 3: Open up the tool after validation

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GET INFORMATION: EPILEPSY.COM

TAKE ACTION: ENDEPILEPSY.ORG

24/7 HELPLINE: 1.800.332.1000

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